



Biglino, G., Layton, S., & Wray, J. (2017). Beyond Heart Symbolism: Artistic Representation of Narratives of Congenital Heart Disease. *JAMA - Journal of the American Medical Association*, 318(18), 1740-1742. <https://doi.org/10.1001/jama.2017.14285>

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BEYOND HEART SYMBOLISM: ARTISTIC REPRESENTATION OF NARRATIVES OF CONGENITAL HEART DISEASE

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“...only a moving image created by ultrasound could echo its sound and shape, could make visible the joy that dilates it and the sadness that tightens it...” (M. de Kerangal) [1]

The heart is an organ charged with extraordinary symbolic value featured in art across time. Contemporary clinically rooted representations of the heart have appeared recently in exhibits in the UK by fashion and portrait photographer Kirsty Anderson, who mounted a photograph display of patients with congenital heart disease at Kelvingrove Art Gallery & Museum in Glasgow accompanied by first person stories relating to each portrait (see: <https://thepsychologist.bps.org.uk/volume-28/march-2015/scars-celebration-life>); and by artists Tim Wainwright and John Wynne, who employed photography, film and sound to recount the experience of transplantation and organ donation in a Hunterian Museum exhibit in London (see: <https://www.rcseng.ac.uk/news-and-events/events/calendar/transplant-and-life/>). In both cases, the voice of the patient was an integral component of the artwork itself.

Here we describe how a participatory arts practice can lead to co-creating original artwork incorporating the voice of several patients and families. With “Heart Narratives”, a 165 x 85 cm wall-mounted panel (Fig.1), British artist Sofie Layton aimed to represent the language and narrative of congenital heart disease (CHD). Layton was artist in residence in 2015-2016 at Great Ormond Street Hospital for Children in London. On the hospital ward or through creative workshops [3], the artist worked with children with CHD, parents, researchers, and practitioners to explore imagery and to develop a visual representation of their narratives of illness. From a clinical standpoint, the artist engaged with adolescents with repaired CHD (including transposition of the great arteries, tetralogy of Fallot, and hypoplastic left heart syndrome) and parents of babies on the paediatric cardiac wards (including diagnoses of hypoplastic left heart syndrome and Di George syndrome). The panel is composed of equally spaced A6-sized metal plates (either copper or aluminium), onto which is screen-printed a heart image in a range of colours and sizes. As part of the process, participants were invited to choose a plate that most resonated with them in terms of material and colour, and they then embossed it with elements directly relating to their narrative. Small images delicately embossed around a central velvet flocked heart thus become symbols for ambitions, memories, desires, states of being. Shining suns, whirling spirals, spinach leaves, brick walls, the stripes of a tiger – they all tell stories. Burning flames speak of aspirations and resilience in adolescents that grow up with congenital heart disease. A spinach leaf (Fig.2) tells a story of acceptance that a favourite food cannot be eaten because of anti-coagulant medication. And interposed between these stories, the artist has placed direct quotes from conversations that took place on the ward or during workshops, just very few yet resonating words. “My new heart is red and it pumps”. “My daughter was born with half a heart”. “My heart is a soldier, it’s been through wars but it’s still fighting and I am really proud of it”. The result is less confrontational than an approach that may use a medium like photography to directly document or represent the effect of living with CHD. But it is the experiential

component that shines (literally), stories that have been collected and represented by an artist who effectively becomes a conduit for the stories themselves.

The setting for the piece was an important consideration. In discussing the witnessing of the pain of others, Susan Sontag wrote that images of pain “demand the equivalent of a sacred or meditative space in which to look at them” [4]. The artist created a site-specific installation for the panel [5] in the gallery-like corridor linking Great Ormond Street Hospital to the adjacent Institute of Child Health. By placing the artwork in that physical link between the hospital and lab, between patient and researcher, the artist was able to engender a strong feeling of the interconnectedness of patients, families, researchers, surgeons, and nurses, and highlight a broader collective narrative beyond the tens of stories re-presented on the panel (whether embossed or quoted directly) linked to the space in which those stories developed.

Placement in the working corridor, rather than in an exhibit space, also meant the installation could be directly experienced by medical professionals and researchers who could reflect –even in passing– on the choral piece or on elements of individual stories (Fig.3). As it emerged, hospital staff were struck by the beauty of the artwork, considering its content and its context [6]. One clinical nurse specialist remarked: “The installation reminds staff that there is a person behind that heart, scan or medical image, and staff should consider the whole person and how that person feels about their heart” [6]. The collection of images represent an activity and process [7] that encouraged patients and their families to express moments or elements significant to them as they navigated their condition [8], and the installation offers physicians involved in the care of young people growing up with congenital heart disease with a different opportunity to reflect on a “dimension of data” [7] which can be overlooked: the narrative, the story, the spinach leaf, the shining sun, the joy that dilates the heart, the sadness that tightens it.

“What is the place of the artist in the clinic, where the aim is not art therapy as such but the elucidation of meanings that are difficult to specify, that cannot easily be put into words?” [9]. As artist Deborah Padfield suggests, the artist’s role in medical context is to *mediate* the process and *represent* the landscape of illness using creative techniques that transform a concept into a tangible visual form [10]. As beautifully described by Oliver Sacks, the artist can receive a reality from the medical/scientific domain, and can “give a *reality* back” [11]. “Heart Narratives” is an attempt to give reality back, suffused with beauty, life, voice, and authenticity, to children with congenital heart disease and their families and caretakers.

Acknowledgments

Sofie Layton's residency at Great Ormond Street Hospital for Children in London was generously supported by the Wellcome Trust, the Blavatnik Family Foundation and GOSH Arts. Images are courtesy of George Eksts and are reproduced with consent.

Figure legends

Figure 1: The "Heart Narratives" panel created by artist Sofie Layton during her residency at Great Ormond Street Hospital for Children in London.

Figure 2: Detail of one of the metal plates embossed –in this case– by a patient with congenital heart disease, where elements of his journey (e.g. the spinach leaf representing food that cannot be eaten because of anticoagulant medication) become part of the collective narrative piece.

Figure 3: Viewers could experience the "Heart Narratives" panel as part of Sofie Layton's installation at Great Ormond Street Hospital for Children.

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